CAREGIVER STRESS & COPING

The Journey Through Caregiving
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North Dakota Family Caregiver Project
North Dakota State University

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CAREGIVER STRESS & COPING

Caregiving, or “providing direct care,” brings to mind nurturing a small child, caring for the chronically ill, or comforting a bereaved family member. Well planned caregiving, at its best, can be healthy and fulfilling. However, there is another side to caregiving. The words often used to describe the “dark side of caregiving” include: exhaustion, anger, and abuse. To be a capable and understanding caregiver, you must equip yourself with the knowledge and support needed to do an exceptional job. Caregiving for family and friends often arrives on the “heels of a crisis” and whether you are a trained professional or a volunteer, you can be “caught off guard.” You may not be prepared for the daily demands that caregiving requires. Often the difference between good intentions and actual tasks fulfilled is rest and support.

The following pages cover the subject of caregiving in multiple ways, including:

- Practical ways to help and support the caregiver and care recipient.
- Tapping into the network available for caregivers.
- Planning for the future.
How do I make the decision to become a caregiver?

Often the decision to become a caregiver is made during a hospitalization or a serious illness. At a time of crisis it becomes obvious that the elderly loved one is no longer able to live independently and alternative living arrangements are necessary. To determine the best living options for the loved one, the whole family should be involved in the decision-making process. If elderly loved ones are capable, they should also be involved in planning for their future. Making the decision to become a caregiver should not be taken lightly. Being thrown into the role of caregiving unexpectedly and without the opportunity to equip oneself emotionally will be very difficult. If possible, becoming a caregiver gradually will not only make the adjustment easier, but will also give the caregiver time to gain basic caregiving skills. Successful caregiving is a joint family decision whether the care recipient is in your home or in a nursing home.

Short-term intensive caregiving is often more easy to accept because we see the disability as temporary with the care recipient recovering. The choice of becoming a long term caregiver will take the individual through stages of caregiving that are often referred as a “career of caregiving.”
The following questions can serve as a guide for families trying to make good decisions about the future care of their loved one.

1. What housing options are possible? Will your loved one move in with a family member, or will the family member move in with the dying loved one?

2. Who will be the principal caregiver?

3. What involvement will siblings have in providing care?

4. Which responsibilities of care can be shared? By whom? (Supervising medications, shopping, doctors, day care, etc.)

5. Is communication open and honest between caregiver and the elderly person?

6. Do family members share feelings and information?

7. What is the person’s financial situation?

8. What are the sources of income for the elderly loved one? (Social Security, private pension, annuities, stocks, interest, IRA’s, CD’s)

9. Is their current medical coverage adequate?

10. Has anyone consulted an eldercare attorney?

11. Has the elderly person transferred any assets?

12. How do you feel about having someone die in your home?

13. How do you feel about caring for the personal needs that your loved one will need?

(Adapted Caregiver Guide)
Love and admiration between family members will increase the potential for handling an emergency successfully. There is a greater likelihood of success for positive caregiving in these circumstances. By comparison, when real caring is absent, a loved one’s needs may quickly become oppressive. Caregiving is a test of the health of any relationship.

Where the care recipient will live while being cared for can be a difficult decision. Relocating care recipients can cause the adjustment time to be longer, more frustrating and less satisfying for a time. Thoughtful decisions and planning prior to the situation will make the process and transition smoother.

The caregiver must help the individual to remain as independent as possible. Overall, retaining more independence and dignity will benefit both the caregiver and the care recipient.

Deciding to care for a dying person at home represents a commitment to quality care and to preserving the person’s ability to live out the remainder of life with dignity. This commitment can also be made by caregivers who choose to have the person remain in the hospital. For a patient who is still hospitalized, the caregiver can act on this commitment by ensuring good care and the maintenance of personal dignity. (Sankar, 11)

In order to be a successful caregiver, one needs the ability to continually

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<th>The varying needs of care recipients may include:</th>
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<td>• Companionship</td>
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<td>• Medication supervision</td>
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<td>• Running errands such as groceries/mail</td>
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<tr>
<td>• Transportation to an appointment</td>
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<td>• Bathing</td>
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<tr>
<td>• Dressing</td>
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<tr>
<td>• Walking</td>
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<td>• Use of toilet</td>
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assess if changes are necessary for any and all family members as the caregiving situation evolves. Regardless of whether you became a caregiver through choice, perceived necessity, or circumstance the degree of fulfillment for all concerned depends upon your approach.
What are the stages of caregiving?

The stages of caregiving that you encounter will be smoother when management and flexibility are built-in components to the experience. This portion of the caregiving module will address some of the typical stages found in caregiving. Looking at the multiple stages in the process of caregiving will help us to understand the difficulty in change. As we look at the stages of caregiving we find transitions from a beginning, to a middle, and to the end of the process.

In the book Profiles in Caregiving by Carol S. Aneshensel (349-353) these three stages and the transitions from one to another encompass what is recognized as a “caregiving career.”

Initially, you will recognize the increasing need for help and the decreasing amount of independence that your loved one retains. At this point you observe the caregiving role unfold before you and slowly begin to assume the obligations and responsibilities of such a role. As these transitions occur, you must accept the deterioration and realize the emerging issues that are associated with the illness. A flexible caregiver will develop management skills necessary to cope with these changes. Being able to understand that the course of the illness is irreversible will help the caregiver through those small and large transitions.

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<th>Stages of caregiving include:</th>
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<td>1. Preparation for the role.</td>
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<td>2. Completing the tasks and responsibilities of caregiving.</td>
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<td>3. Detachment from various levels of caregiving.</td>
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As you begin to complete more and more daily tasks for your loved one you are transitioning into the second phase of caregiving. The potential for stress will increase as demands increase. However, you must recognize that an answer for handling a certain challenge will change as the situation progresses. In this stage it is important to take advantage of volunteers and other resources within the community to assist with caregiving. By using formal supports such as adult day care, in-home health care, and respite care you can get the support you need to continue doing an effective job of caregiving.

As the caregiving role becomes overwhelming and exhausting you may recognize the need to pass your role over to an institution that can provide for the care as well as the safety needs of your loved one. At this point caregivers will often feel guilt and failure for not being able to continue meeting their loved one’s daily needs. Acceptance of this change will often result in learning new strategies to support their institutionalized loved one.

Transitioning out of the primary caregiver role can be a difficult adjustment. The social structure that you had before you began caregiving may not be the same. Do not expect your life to return to “normal” immediately. It will take time to slowly develop your daily routine and become involved in the many venues of life. Becoming part of a support group can help this transition process.

No matter what stage of caregiving we have transitioned into or out of, the management of care needs to be done with respect and acceptance of responsibility. Caregivers who are engaged in the same stage at the same
time will not necessarily experience the same conditions. Rather, each caregiving experience will contain different circumstances and different transitions that will vary substantially.

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<th>Six sub-stages that caregiving can be broken down into:</th>
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<td>1. <strong>The Expectant Caregiver:</strong> You have a growing concern that within the next 12 to 18 months you will need to become a full-time caregiver for your aging loved one. This is your time to prepare.</td>
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<td>2. <strong>The Freshman Caregiver:</strong> You have been caring for an aging relative for 6 to 18 months. This is your entry into the caregiving role. Now is the time to shape your caregiving personality.</td>
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<td>3. <strong>The Entrenched Caregiver:</strong> You’ve been involved in your care recipient’s care for two to five years. It’s time to develop a routine that will provide comfort for you and your care recipient.</td>
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<td>4. <strong>The Pragmatic Caregiver:</strong> You’ve been a caregiver for more than 5 years. You’ve settled into your role and your routine.</td>
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<td>5. <strong>The Transitioning Caregiver:</strong> You’ve been a caregiver over a period of several years and your recipient’s condition has taken a turn for the worse. This is your opportunity to mourn for your loved one, even before death.</td>
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<td>6. <strong>The Godspeed Caregiver:</strong> Your role as caregiver ended more than two years ago. You now become a strong support for other caregivers who are going through hard trials in earlier caregiving stages.</td>
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(Adapted Miller, 2000)
What is caregiver stress?

According to Webster’s Dictionary, stress is a physical, chemical, or emotional factor that causes bodily or mental tension. It is a reaction to changes that require adjustments or responses and our stress level will depend upon how we respond to these adjustments. Early on in your caregiving experience you will notice increased stress. Accepting a caregiver role will cause you to redefine your life. Recognizing the changes that come with your new role, yet still having expectations of life returning to normal during the caregiving period, will cause immense stress. We must try to understand that each new day will probably be different, and the need to remain flexible is of utmost importance. For instance, the older adult’s mind or physical strength may be deteriorating daily, bringing about changes for both the caregiver and care recipient.

To remain useful in caregiving it will be necessary to know the signs and origin of your stress. Successful caregiving is a combination of securing help when needed, yet flourishing with each changing role as a caregiver. Recognizing the stressors you can eliminate, gives your courage and enthusiasm to take control over changes that previously would have overwhelmed you. You must remember that you cannot change people and that you only have the power to change yourself. If your outlook is positive, it will help you to look forward to each new day with enthusiasm instead of dread.
What causes caregiver stress?

It is crucial that you understand what is causing stress in your life. It is only by being conscious of what is affecting you negatively that you will be able to avoid being overwhelmed at every turn of event. Recognizing how you came to the role as a caregiver can be the first step to overcoming caregiver stress. Sometimes when we have had no choice to become a caregiver we can become angry, impatient, and question the fairness of the circumstance.

### How did you get put in the caregiver role?

- Your choice
- Perceived obligation
- Attachment or relationship to that older adult
- Your ability to deal with the situation
- You perceived it as your responsibility
- Your spouse needs care
- A child born with a birth defect

Caring for an older adult suffering from dementia is more difficult, time consuming, and frustrating because you may have undue expectations based on how they used to be instead of how they are now. There is no question that dealing with physical limitations is often less stressful than mental limitations.

The quality relationship you had with the care receiver in “good times” will effect expectations that you may bring to the current caregiving
situation. A difficult relationship may be strengthened or further disintegration may take place, causing regrets and resentments to build. If the quality of the relationship is poor the assistance of a professional may help. Relationships can be strengthened through much effort, compromise and willingness to sacrifice.

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<th>Caregiver stress can be caused by any of the following:</th>
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<td>▪ Care receiver’s behavior and attitude</td>
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<td>▪ Physical and emotional components of care</td>
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<tr>
<td>▪ Adjusting to work and caregiving</td>
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<tr>
<td>▪ Care receiver’s financial problems</td>
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<td>▪ Adjustments of caregiving within the family</td>
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**If you recognize these early warning signs, you can try to take steps to relieve them and possibly avoid serious troubles.**
What are warning signs of caregiver stress?

Many times we are too busy caregiving and do not recognize the beginning indications of stress. Over time the constant physical and emotional demands can take a toll. Changes in our behavior or in our mental health can be signals that we are living with too much stress.

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<th>Warning signs that may indicate high stress include:</th>
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<td><strong>Physical.</strong> Headaches, appetite or weight changes, feeling tired all the time, changes in sleep habits, muscle aches, getting sick often, stooped posture, sweaty palms, neck pain, weight gain or loss.</td>
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<tr>
<td><strong>Emotional.</strong> Anger, sadness or crying spells, irritability or short temper, worry or anxiety, discouragement, trouble relaxing, emptiness or loss of direction, looking for magic solutions, inability to concentrate, frequent mood swings.</td>
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<tr>
<td><strong>Behavioral.</strong> Increased use of drugs or alcohol, trouble concentrating, avoiding decisions, low productivity, forgetfulness, boredom, over-reacting, acting on impulse, changing jobs often.</td>
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<td><strong>Relationships.</strong> Problems with marriage or children, intolerance of others, fewer contact with friends, nagging, lowered sex drive, loneliness, resentment.</td>
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(Adapted Jolly, 1996 & Caregiving: Stress Management and Burnout Prevention)
How do I manage caregiver stress?

It is vital to assess what kind of help you need when signs of stress become apparent. The quicker you take action to get help the better chance you have of successfully avoiding the level of stress that could lead to illness.

### Healthy choices for dealing with stress may include:

- Exercise
- Get enough sleep
- Eat proper food
- Take time for hobbies
- Ask for support from our families, friends, or community resources
- Take care of your physical appearance
- Accept that there are events you cannot control
- Stop smoking
- Set realistic goals and expectations
- Be forgiving
- Communicate feelings

Advance planning can strengthen the potential for success in managing stress.

Former caregivers have made a variety of suggestions to help current caregivers maintain good mental and physical well-being. Some of these suggestions include:

- Locate an individual or a support group with whom you can communicate your feelings, frustrations and anxieties
• Streamline caregiving techniques to help lower stress
• Reassess your beliefs, feelings, and insights and draw strength from your core value system
• Create and implement self-help strategies
Things the care receiver can do for the caregiver to relieve stress:

1. If you can possibly do it for yourself, do it, and be happy that you can.

2. Express good manners… say thank you for the smallest things. Everyone wants and needs to be appreciated.

3. Do your part to boost the entire family’s morale.

4. Your caregiver has a life other than caring for you, so rejoice when they have an opportunity to “go” without you.

5. Laugh when things become tense. Many times that is all one can do.

6. Be agreeable to change. Things cannot always be done like they once were.

7. Smiling is a real upper for the one who does the smiling as well as the one who receives it.

8. Think before you complain and ask yourself, “Will this help?” Chances are your complaints only agitate the condition and anyone within earshot.

9. Look at your disease or disability head on, and do what is necessary to make your life and that of your caregiver as pleasant as possible.

10. Never be demanding and remember no one is a slave to another person. Compassion and understanding go a long way.

11. Practice patience and moderation in all things.

12. Demonstrate your love in every possible way. Let it radiate to all God’s creatures.

(Loflin, 2001)
What are the barriers to managing caregiver stress?

The more stressed we are in a caregiving situation, the more some of the symptoms of stress get in the way of making changes. Recognizing the barriers to relieving stress is essential to living more successfully with stress.

### Barriers to managing stress include:

- Trying to solve too many problems at once makes change overwhelming.
- Blaming others, “the system,” or “fate” prevents action.
- The buildup of stressors in our lives may affect our judgment and our initiative.
- Using drugs or alcohol as substitutes for resolving problems increases stress.
- A negative outlook makes us believe nothing can change.

(Jolly, 1996)
What is caregiver burnout?

“Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude, from positive and caring to negative and unconcerned. Burnout can occur when caregivers don’t get the help they need, or if they try to do more than they are able physically and financially” (Caregiving: Stress Management and Burnout Prevention). Chronic stresses will reduce the quality of caregiving and your rapport with the loved one will suffer, your career may collapse, and as you struggle to cope, your physical and mental health may deteriorate.

As a caregiver you may be unaware how quickly the quality work we are doing can deteriorate. Unknowingly, loved ones may be a contributing factor to the burnout, since their anxiety, increasing pain and/or potential dementia may make them more of a challenge, thereby stretching your caregiving to its thinnest point.

What causes caregiver burnout?

Caregivers often tend to neglect their own emotional, physical, and spiritual health, because they are too busy tending to the needs of others. The demands put on caregivers by themselves and other family member can easily become overwhelming. Anguish and exhaustion are descriptive words used to partially describe “burnout,” which all too often leaves a caregiver unable to overcome the obstacles without adequate resources to solve them.
Causes of caregiver burnout may include:

- Demands from care receivers and others in the environment.
- Apparent helplessness of the care receiver’s condition.
- Unreasonable burdens put on yourself.
- Role confusion.
- Lack of control over money, resources, etc.
- Conflicting policies and procedures when trying to access support services.

Even in the best of circumstances a caregiver on any given day may feel like quitting, although family caregivers are usually not left with that option. Studies show that caregivers who care beyond their physical and mental ability face the risk of serious illness and even death. As you assess the possible symptoms of potential burnout, they can actually alert you to the dangers you are facing. Do not mask the symptoms with medication or by running away, instead acknowledge the problem and realize that you need to quickly make changes.

**What are symptoms of caregiver burnout?**

Continuous crying can be one clear indicator of depression and hopelessness. If it is hard to gather the energy to get out bed and face the responsibilities of the day or if you find yourself continually unhappy or “down” while you are with the care recipient, you may have depression. It
is not unusual for anyone to feel sad at times, but remaining down over time can indicate that you need help.

Feeling lonely or alone in your caregiving does not set up a healthy support network. Ask yourself:

1. Have you isolated yourself from potential helpers?
2. Have you lost contact with people you used to count on for social and mental encouragement?
3. Do you find yourself retreating from others?

If your response is yes to these questions then you are running the risk of deepening your isolation and increasing “burnout.” Recognizing the balance of family and friends is necessary to a healthy caregiving experience and is crucial to warding off “burnout.” Physical and mental symptoms such as worry, nervousness, tension, and fear can increase anxiety to the point of being ineffective as a caregiver. When these concerns are present the caregiving environment can become harsh and potentially abusive. The caregiver will often make more mistakes and the care recipient may notice the anxious moments.

Even normal situations can cause a caregiver who is approaching “burnout” to be short-tempered, edgy, and cross. This impatience extends to all who come in contact with the caregiving situation. These caregivers are no longer able to draw upon inner or outer resources that are available to them or that they previously used before “burnout.” Lack of tolerance is a clear signal that the caregiver is under too much pressure and stress.

It is not unusual for a caregiver to experience anger, but when it shows up in bouts of rage, antagonistic at the least little thing, and/or continuous outward resentment towards the care recipient or the
circumstance in which they find themselves, it is time to seek anger management. Left untreated the entire situation can be dangerous for the care recipient and debilitating for the caregiver.

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<th>Symptoms of caregiver burnout include:</th>
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<td>▪ Withdrawing from friends, family, and other loved ones.</td>
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<td>▪ Losing interest in activities previously enjoyed.</td>
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<td>▪ Feeling blue, irritable, hopeless and helpless.</td>
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<td>▪ Experiencing changes in appetite, weight, or both.</td>
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<td>▪ Experiencing changes in sleep patterns.</td>
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<td>▪ Getting sick more often.</td>
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<td>▪ Feeling you want to hurt yourself or the person for whom you are caring.</td>
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<tr>
<td>▪ Becoming emotionally and physically exhausted.</td>
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<td>▪ Being irritable.</td>
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**How can caregiver burnout be prevented?**

If “burnout” symptoms are apparent to a caregiver there are steps that can be taken to relieve, change, or prevent further deterioration. The most useful steps involve identifying the symptoms and causes, acknowledging the symptoms, and focusing on finding realistic solutions to the problem. If you do not take action to eliminate “burnout,” you will needlessly exhaust yourself and your resources.
Steps you can take to prevent caregiver burnout include:

1. Find someone you trust, such as a friend, co-worker or neighbor, to talk to about your feelings and frustrations.

2. Set realistic goals, accept that you may need help with caregiving, and turn to others for help with some tasks.

3. Be realistic about your loved one’s disease, especially if it is a progressive disease such as Parkinson’s or Alzheimer’s.

4. Don’t forget about yourself because you’re too busy caring for someone else. Set aside time for yourself, even if it’s just an hour or two. Remember, self-care is not a luxury. It is an absolute necessity for caregivers.

5. Talk to a professional. Most therapists, social workers, and clergy members are trained to counsel individuals dealing with a wide range of physical and emotional issues.

6. Take advantage of respite care services. Respite care provides a temporary break for caregivers. This can range from a few hours of in-home care to a short stay in a nursing home or in assisted living facility.

7. Know your limits and take a reality check of your personal situation. Recognize and accept your potential for caregiver burnout.

8. Be honest with yourself about your capabilities and goals. Set small, achievable goals for yourself and your caregiving.

9. Educate yourself. The more you know about the illness, the more effective you will be in caring for the person with the illness.

10. Develop new tools for coping. Remember to lighten up and accentuate the positive. Use humor to help deal with everyday stresses.
### Steps you can take to prevent caregiver burnout include:

11. Stay healthy by eating right and by getting plenty of exercise and sleep.

12. Accept your feelings. Having negative feelings, such as frustration or anger, about your responsibilities or about the person for whom you are caring is normal. It does not mean you are a bad person or a bad caregiver.

13. Join a caregiver support group. Sharing your feelings and experiences with others in the same situation can help you manage stress, locate helpful resources, and reduce feelings of frustration and isolation.

14. Contact your area Agency on Aging or local chapter of AARP for information on services available in your area such as adult day services, caregiver support groups, and respite care.

### What are some coping skills for caregivers?

Coping is the way you deal with and attempt to overcome problems and difficulties associated with caregiving. Those who handle stress properly have learned coping strategies and are flexible in gearing their responses to each new challenging situation. They generally have a positive outlook and look for ways to take control of their life.
## Coping skills for caregivers include:

### Stress Management
- Exercise.
- Talk to someone about worries, concerns.
- Know your limits. Set limits.
- Make time for fun.
- Know what you have to do. Do one thing at the time.
- Know it’s O.K. to cry.
- Avoid self-medication.

### Time Management
- Know that some time will be spent on activities beyond your control.
- Make a daily “to do” list.
- Do the most important/difficult things first.
- Save up errands to do at once.
- Take along a small task if you go somewhere you know you will have to wait.
- Do an appraisal of the things you must do. Delegate what you can. Forget what is unnecessary.

### Decision Making
- Define and clarify the issue.
- Set up criteria that any solution or decision should meet. For example: there is enough time; it is affordable.
- Select the best possible solution for everybody involved.
- Design a plan of action.

### Life-style Management
- Exercise.
- Eat right.
- Get enough rest.
- Take time to relax.
- Maintain a sense of humor.
- Get regular medical and dental check-ups.
- Develop and use a support system.

(Adapted Haigler, 1998)
FINDING AND USING COMMUNITY RESOURCES

Even in the most rural of communities, families often do not fully explore or use the community services available to them for caregiving. Either they are unacquainted with the services or they don’t know how to plan within the system.

It is a time consuming and often frustrating experience to find agencies that will supply information and will refer older people or their caregivers to the appropriate service needed at the time.
How do I identify formal support services?

A recognizable part of the formal support network is the Medicaid system of home health services. Many older adults have the misperception that Medicaid will fund the home health services that they need at this time. When confronted with the actual service limitations, the older adult will become irritated and let down.

To qualify for services under the Medicaid Waiver for the Aged and Disabled program, and individual must be:

- A Medicaid recipient (meets income eligibility requirements)
- Screened at nursing facility level-of-care
- At least 65 years of age or disabled by Social Security Disability criteria
- Capable of directing his/her own care
- Living in his or her own home or apartment (not in a dormitory or other group housing)
- Able to have his or her service/care need(s) met within scope of the Waiver

(Adapted Home & Community-Based Services: North Dakota’s Medicaid Waiver for the Aged and Disabled)
<table>
<thead>
<tr>
<th>Home &amp; Community Based Services available through North Dakota’s Medicaid Waiver for the Aged and Disabled:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HCBS Case Management</strong> assesses needs, helps with care planning, provider selection, referrals and service monitoring.</td>
</tr>
<tr>
<td><strong>Respite Care</strong> provides temporary relief to full-time caregivers.</td>
</tr>
<tr>
<td><strong>Personal Care Service</strong> helps with bathing, dressing, transferring, toileting, and supervision.</td>
</tr>
<tr>
<td><strong>Adult Family Foster Care</strong> provides a safe, supervised family living environment, 24-hour per day in a state licensed setting.</td>
</tr>
<tr>
<td><strong>Chore Service</strong> includes snow removal and heavy cleaning.</td>
</tr>
<tr>
<td><strong>Homemaker Services</strong> provides house cleaning, laundry, and/or meal preparation services.</td>
</tr>
<tr>
<td><strong>Emergency Response System</strong> (Lifeline) provides telephone emergency response</td>
</tr>
<tr>
<td><strong>Non-Medical Transportation</strong> transports or escorts clients for essential needs such as grocery shopping social security office visit, etc.</td>
</tr>
<tr>
<td><strong>Adult Day Care</strong> provides at least three hours per day of attended care in a group setting.</td>
</tr>
<tr>
<td><strong>Environmental Modification</strong> modifies the home to enhance client’s independence (e.g. install safety rails).</td>
</tr>
<tr>
<td><strong>Specialized Equipment</strong> provides special equipment reducing the need for human help.</td>
</tr>
<tr>
<td><strong>Training Family Member(s)</strong> improves skills of non-paid primary caregiver in the family.</td>
</tr>
<tr>
<td><strong>Adult Residential Service</strong> available to individuals living in a social model Alzheimer’s facility.</td>
</tr>
</tbody>
</table>

(Adapted Home & Community-Based Services: North Dakota’s Medicaid Waiver for the Aged and Disabled)
Another government funded program is the Services Payments for the Elderly and Disabled (SPED) program & Expanded SPED program. These programs pay for a variety of services to sustain individuals in their homes and communities. Services funded by these programs are provided by both independent contractors and agency providers who meet the criteria.

### SPED program criteria:

- Liquid assets of less than $50,000.
- Inability to pay for services.
- Impaired in four Activities of Daily Living (ADLs) involving basic needs such as bathing, dressing, toileting, etc. OR in five Instrumental Activities of Daily Living (IADLs) that require a higher level of cognitive or physical ability to perform such as driving, managing money, shopping, etc.
- Impairments must have lasted or are expected to last three months.
- Is not eligible for Aged & Disabled Waivers
- Is not living in an institution, dormitory, or congregate housing.
- The need for service is not due to mental illness or mental retardation.
- Is capable of directing own care or has a legally responsible party.
- Has needs within the scope of covered services.

(Adapted Home & Community Based Services: Services Payments for the Elderly and Disabled (SPED) program & Expanded-SPED program)
<table>
<thead>
<tr>
<th>Expanded SPED criteria:</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Receives or is eligible for Medicaid</td>
</tr>
<tr>
<td>▪ Receives or is eligible for Social Security Income (SSI)</td>
</tr>
<tr>
<td>▪ Is not severely impaired in the ADLs of toileting, transferring, eating.</td>
</tr>
<tr>
<td>▪ Is impaired in three of four IADLs: meal preparation, housework, laundry, or taking medications.</td>
</tr>
<tr>
<td>▪ Has health, welfare, or safety needs, including supervision or structured environment, otherwise requiring care in a basic care facility.</td>
</tr>
<tr>
<td>▪ Is not living in an institution or dormitory.</td>
</tr>
<tr>
<td>▪ Has needs within the scope of covered services.</td>
</tr>
</tbody>
</table>

(Adapted Home & Community Based Services: Services Payments for the Elderly and Disabled (SPED) program & Expanded-SPED program)
### Services covered under the SPED & Expanded SPED programs:

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case Management</strong></td>
<td>assesses needs, helps with care planning, provider selection, referrals and service monitoring.</td>
</tr>
<tr>
<td><strong>Respite Care</strong></td>
<td>provides temporary relief to full-time caregivers.</td>
</tr>
<tr>
<td><strong>Personal or Attendant Care Service</strong></td>
<td>helps with bathing, dressing, transferring, toileting, and supervision.</td>
</tr>
<tr>
<td><strong>Adult Family Foster Care</strong></td>
<td>provides a safe, supervised family living environment, 24-hour per day in a state licensed setting.</td>
</tr>
<tr>
<td><strong>Homemaker Services</strong></td>
<td>provides house cleaning, laundry, and/or meal preparation services.</td>
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<td><strong>Emergency Response System</strong> (Lifeline)</td>
<td>provides telephone emergency response</td>
</tr>
<tr>
<td><strong>Non-Medical Transportation</strong></td>
<td>transports or escorts clients for essential needs such as grocery shopping social security office visit, etc.</td>
</tr>
<tr>
<td><strong>Family Home Care</strong></td>
<td>reimburses a family caregiver who meets the relationship requirements defined by state law and resides in a client’s home 24-hours per day.</td>
</tr>
<tr>
<td><strong>Environmental Modification</strong></td>
<td>modifies the home to enhance client’s independence (e.g. install safety rails).</td>
</tr>
</tbody>
</table>

(Adapted *Home & Community Based Services: Services Payments for the Elderly and Disabled (SPED) program & Expanded-SPED program*)

To apply for these government funded programs, please contact the County Social Service Office in your area.
How do I know what formal services are available in each county of North Dakota?

North Dakota Family Caregivers Mapping Project is an on-line database that identified senior services through North Dakota and organized them according to counties. This database can be accessed on the web at: www.ndsu.edu/ndsu/caregivers.

Information and Referral is an on-line database of services available to seniors in different counties throughout North Dakota. This database can be accessed on the web at: www.ndseniorinfoline.com or by calling 1-800-451-8693.

Rural Response Coalition is a program funded through Lutheran Social Services of North Dakota. The programs listed on this database are available to farm and ranch families, individuals, and communities. It can be accessed on the web at: www.lrrnd.org or by calling 1-800-950-2901.

*Disclaimer: ND Family Caregiver Support Project is not responsible for the accuracy of information located on these web pages.
How do I select a non-agency provider?

Before you select an in-home service provider, there are many things you should consider. Think about your lifestyle, the type of services you will need, and your future needs.

### Tips for interviewing in-home providers include:

1. What training does the candidate have?
2. What is the candidate’s work history and experience?
3. Describe your needs; ask if the candidate is capable of performing these tasks.
4. Does the candidate have the skills or knowledge to meet your special care needs?
5. Does the candidate have any allergies or other medical/physical health related problems that may interfere with your specific care needs?
6. If the candidate will be providing you with transportation, verify his/her driver’s license and insurance and ask if their vehicle is safe.
7. If the candidate will be driving your vehicle, verify his/her driver’s license and check with your auto insurance agent about coverage in case of accidents.
8. If food preparation is needed, ask if the candidate has experience cooking for others.
9. Ask what the candidate’s expectations are regarding vacation and time off.
10. If you have pets, ask if the candidate is agreeable to providing care for them.
11. Ask the candidate for references.
12. At the end of the interview, tell the candidate when you will get back to him or her.

(Adapted In-Home Services: Selecting a Non-Agency Provider)
Consider obtaining a criminal background check through the Bureau of Criminal Investigations. You can also contact the Department of Health, Division of Health Facilities for information about a Certified Nurses Assistant (CNA); or the ND Board of Nursing for information about a Nurse Assistant (NA), Licensed Practical Nurse (LPN) or Registered Nurse (RN).

When you call the references, ask about patterns of attendance and punctuality, attitude and competence.
Do I need a written agreement with my in-home service provider?

When you decide which in-home service provider you would like to hire you should have a written agreement that sets forth the conditions of employment and is agreed upon, signed and kept by both parties.

<table>
<thead>
<tr>
<th>The written agreement may include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Who is responsible for the payment of transportation cost, meals, Social Security and other fringe benefits.</td>
</tr>
<tr>
<td>2. Rate of pay, days and hours of employment, days off, vacations, and whether or not you will be withholding taxes</td>
</tr>
<tr>
<td>3. Schedule of tasks and set working hours.</td>
</tr>
<tr>
<td>4. How and to whom the provider will communicate any change in your condition or behavior.</td>
</tr>
<tr>
<td>5. A statement of confidentiality that prohibits the provider from discussing any personal information about you.</td>
</tr>
<tr>
<td>6. How medical emergencies will be handled. Include names and telephone numbers of emergency contacts.</td>
</tr>
<tr>
<td>7. A requirement that all receipts accompany all purchases made on your behalf.</td>
</tr>
<tr>
<td>8. A clarification of the provider’s responsibilities regarding meal preparation, routine housework, laundry, etc. when you have family/friends as daytime or overnight guests.</td>
</tr>
<tr>
<td>9. Your preference regarding smoking in your home.</td>
</tr>
<tr>
<td>10. How much notice each party should give when one decides to discontinue services.</td>
</tr>
</tbody>
</table>

(Adapted In-Home Services: Selecting a Non-Agency Provider)
How do I develop an informal support network?

The difference between thriving and surviving for many older people is the neighbors, friends, and other helpers who live nearby. They are vital to the older person’s ability to live independently. Many times this help is more acceptable than the help from a formal agency. A caregiver will benefit from tapping into an existing informal support network comprised of neighbors, family, friends, volunteer teenagers, and other volunteers in the community. The care receiver already has benefited from these contacts in the past and trusts their efforts to help them.

Knowing the older adults “typical day” can be valuable is assessing who has daily contact and what level of help each individual gives to them. This process can usually be accomplished by following elders’ footsteps throughout the day. It will become apparent who their social contacts are and who they can depend on and for what. Identifying the people that could be part of the older person’s network can require an extensive effort to build a network of willing individuals to provide these informal supports.

Neighbors who become involved are often the pillars of support needed to keep older people in their homes. They may help by just keeping in touch or running errands for mail and groceries. Helping the older adults’ neighbor by doing jobs they don’t like could extend the time they remain within the informal support network. Another strategy is to offer to pay the neighbor for providing on-going support for your loved one. Living in the same neighborhood for decades has been a common practice for many older adults. These individuals have often established good relationships and strong friendships with their neighbors. These kinds of
neighbors provide a powerful resource that can make a real difference in your older loved one remaining within the neighborhood for a longer length of time.
PLANNING FOR THE FUTURE

Planning for the future to meet potential increases in caregiving demands begins with gathering information. Assessing and evaluating your loved one’s needs can be as simple as tapping into the vast knowledge that your loved one might have concerning who or what has enabled them to retain their independence up to this point. It can also be as complex as being a long distance caregiver with limited knowledge of the extent of abilities and independence of your loved one or the kind of supports that are available in his/her community. In order to do future planning for increased caregiving you will need to get a complete picture of the current status of the care recipient, the strengths of the available family, friends and neighborhood, and the availability of health care services.

How do I assess the needs of an elder?

An important first step in assessing your loved one’s needs is to strive to understand and consider his/her thoughts and feelings before deciding what must be done. Simple things like knowing how well your loved one functions in daily activities such as cooking and managing finances needs to be taken into consideration. As you better understand the day-to-day activities of your loved one you will see the bigger picture of their accessible personal, social, and financial resources from which to draw a caregiving plan. You will be better prepared to make a decision once you understand the whole situation of the care recipient.
Whether you are a long-distance or a nearby caregiver, it is difficult to make a complete assessment on your own. Obtain information from several different sources including:

- Family
- Friends and neighbors
- Current health care providers such as doctors
- Businesses where they shop or that provide deliveries

By observing the ways your loved one receives help from others, you will have an indication of his/her level of independence as well as what help may be needed in the future. In your search for the appropriate level of care necessary it will be important to consider the following:

- Changes being experienced, problems associated with that change, and care necessary to address that challenge.
- Assessing whether the change is short term or long term.
- The amount of help necessary in areas such as:
  - Food/grocery planning
  - Personal care
  - Safety in the home
  - House cleaning
  - Health care/doctor
  - Managing medicine
  - Driving/personal mobility
  - Economic/legal issues
  - Friendship/ companionship
  - Socialization
  - Wellness/exercise

- Mental and physical changes that could create problems, and safety concerns.
Decision-making for the future is important. Unless your loved one has memory problems, discussing future changes will help in the decision-making process. The importance of future planning according to the Caregiver Helpbook, by Vicki L. Schmall, would be to “focus on issues such as declining health, choosing a doctor, long-term care, living arrangements, financial and legal issues, end-of-life decisions, and death and funeral arrangements” (p 148).

Making plans in advance makes difficult choices easier and will decrease the confusion and arguments between and among family members. The care recipient’s desires can also be expressed better before health decline. At the same time care recipients will remain in charge of their lives to the degree they are capable and the result will be preserved dignity and independence.
How do I choose a Doctor?

Choosing a doctor is one of the most important parts of planning for the future caregiver/care receiver situation. Find a doctor whose skills and style of practice suits your needs. Refer to friends or other personal contacts you may have in the community who have been happy with the level of care they’ve received from their doctor.

<table>
<thead>
<tr>
<th>Questions to consider when choosing a doctor:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does your loved one have a primary care physician?</td>
</tr>
<tr>
<td>2. How far do you have to travel to receive health care services?</td>
</tr>
<tr>
<td>3. Does your loved one’s doctor presently reflect the skills necessary to continue to meet an increasing need for care?</td>
</tr>
<tr>
<td>4. Within your community, are there doctors who have an empathetic understanding of the care recipient’s personality and aging process?</td>
</tr>
<tr>
<td>5. How are medical emergencies handled?</td>
</tr>
<tr>
<td>6. What method of communication does the doctor prefer?</td>
</tr>
<tr>
<td>7. Who will answer my questions if the doctor is unavailable or if it is after hours?</td>
</tr>
</tbody>
</table>
**Different types of Doctors**

- **Family Practice** doctors treat all family members (child or adult).
- **Internal Medicine** doctors diagnose and treat nonsurgical disease in adults.
- **General Practice** doctors provide services that are not limited to a specialty.
- **Pediatric** doctors specialize in caring for and treating disease in infants, children, and adolescents.
- **OB/GYN** doctors specialize in obstetric or birthing and gynecology which provides services for the female reproductive system.
- **Nurse Practitioners** are advanced practice nurses prepared in programs specific to women’s health-care including common gynecological problems, routine screenings, and family planning.

**Areas of specialty include:**

- **Acupuncture** is the Chinese practice of inserting needles into a specific exterior body location to relieve pain or to induce anesthesia.
- **Allergy Immunologists** treat allergies and disorders of the immune system.
- **Anesthesiologists** give anesthesia, either general or spinal block, for surgeries and some forms of pain control.
- **Cardiologists** treat heart disorders.
- **Chiropractors** specialize in manipulation and specific adjustment of body structures.
### Different types of Doctors

- **Dermatologists** treat skin disorders.
- **Endocrinologists** treat hormonal and metabolic disorders.
- **Gastroenterologists** treat digestive system disorders.
- **General Surgery** doctors do common surgeries involving any part of the body.
- **Geriatricians** specialize in diseases of old age and aging people.
- **Immunologists** treat disorders of the immune system and allergies.
- **Nephrologists** treat kidney disorders.
- **Neurologists** treat nervous system disorders.
- **Nuclear Medicine** is the use of radioactive materials in the diagnosis and treatment of disease.
- **Oncologists** treat cancer and some other malignant disease.
- **Ophthalmologists** treat eye disorders and do surgeries.
- **Orthopedics** treat bone/connective tissue disorders.
- **Otorhinolaryngologists** treat ear, nose, and throat disorders.
- **Pathologists** interpret and diagnose the changes caused by disease in tissues and in body fluids.
- **Physical Therapists** treats diseases by physical and mechanical means such as massage, regulated exercise, water, light, heat, and electricity.
### Different types of Doctors

- **Occupational Therapists** provide therapy by means of activities that promote recovery and rehabilitation from disease.

- **Podiatrists** provide medical care and treatment of feet.

- **Psychiatrists** treat emotional and mental disorders.

- **Psychologists** treat emotional and mental behaviors.

- **Pulmonary** (lung) doctors treat respiratory tract disorders.

- **Radiologists** evaluate X-rays and related procedures in the diagnosis and treatment of disease.

- **Urologists** treat male reproductive tract disorders and both male and female urinary tract disorders.
How do I communicate effectively with doctors and the caregiving team?

The most important thing to consider when developing good communication among the caregiving team members is to be organized and persistent.

**Plan what you will say before you meet with the doctor…**

1. Write down issues and questions that you wish to discuss.

2. Allow adequate time to communicate and allow everyone time to state their views regarding the care of their loved one.

3. Determine who should be present at the appointment.

4. Don’t hesitate to ask for a second explanation.

5. Don’t use “jargon talk” in end-of-life care.


7. Communicate preferences of race, ethnicity, culture, and religion to the health care team.

8. Take notes during the appointment. Many issues may arise after you leave, and you may forgot what was discussed.

9. Summarize the discussion.

10. Plan for the next step in the care of your loved one.
How do I communicate with the care recipient and others in the support system?

Good communication between and among the caregiver and the care recipient is crucial. Lack of strong communication underlies most problems in a caregiving experience. Explaining the care as we go, will eliminate misunderstanding and confusion. Although we can’t change the continuing progress of the disease we can make the best of a difficult situation through clear communication.

Good communication skills go hand in hand with solid information about the condition of your loved one. Whether it is a short-term or a long-term care commitment, open communication and compassion are essential.

High-quality communication depends on a give and take between all parties and most often is reflected in how well we listen, in what we say or do not say to others, and in how respectful we are of an individual’s ability.

Listening: At the heart of good communication is listening with an open mind. Respecting opinions of others that differ from ours will indicate the depth of our caring since it gives us a view of their feelings and outlook. When caregivers become tired it is hard to be a good listener, especially if we are hearing the same story for the tenth time that day. Our needs, like hunger or exhaustion, can become barriers to our conversations with our loved ones and others. These barriers along with our overall attitude could reduce our ability to listen.
Listening strategies to strengthen your communication with the older adult could include:

- Direct your full attention to the older adult when they speak.
- Provide encouragement for their opinions.
- Acknowledge and confirm their spoken words and body language.
- Use appropriate tone in your voice when you are speaking.
- Assure older adults they have been heard.
- Decrease disturbing noises and activities within the environment.

Communication involves the speaker and the listener. Careful listening is just as important as the right to be heard, both can be done well by expressing yourself clearly.

**When someday comes, how will I decide what to do?**

This could be a theme for talking of the future. Hard topics, not always easy to discuss, can be brought out into the open for consideration when presented in a format of “when someday comes.” Examples of issues you may have avoided discussing could include: identifying when you no longer can care for your spouse in your home; when to leave your family doctor for services of a specialist; funeral plans; financial burdens; and legal affairs. Watching for the right time to bring up subjects, like death, will show your openness to options that previously were avoided. It is wise to have more than one plan and flexibility is the key to the changes required.
How do I choose a Nursing Home?

After you have explored the care options with your loved one, you may come to the conclusion that a nursing home is necessary. Choosing the best nursing home will depend on several factors.

Nursing homes that provide activities for daily living and skilled nursing care are the most common types of facilities. Be sure to explore the details of what is included in the basic services provided by each type of care facility before making your final selection. You want a care facility that offers safety, compassion, quality health care, and handiness yet will allow your loved one to remain as independent as possible. Accurately evaluating your care recipient’s needs and your family’s preferences will make it easier to select a facility.

Factors that affect what kind of care your loved one will need:

- The level of care necessary now and in the future.
- Family preferences
- Monetary resources
- What services are offered within your community.
- Is your relative ambulatory, or non-ambulatory (requires a wheelchair or walker or other walking aid)?
- Does your loved one want a private room?
Checklist for choosing a Nursing Home:

1. Is the facility Medicare certified? Medicaid certified?

2. Does the facility accept Supplemental Security Income residents?

3. Is the facility accepting new patients? Is there a waiting list?

4. Is the licensing and certification for the facility current? Is the license of the nursing home administrator current?

5. Does the nursing home have any specialty care units?

6. Does the nursing home comply with local and/or state requirements?

7. How are the resident’s need for services determined, and how often are they reassessed?

8. What are the resident’s responsibilities regarding the plan of care? Can they be discharged for non-compliance?

9. What services are included in the contract? (ex. Laundry/housekeeping services, shopping for personal needs, help with dressing, bathing, and personal grooming, assistance with medications, transportation, access to telephone, access to religious services)

10. What are the arrangements for medical follow up with the resident’s doctor?

11. May residents maintain their current physician, or does the facility require the use of a staff physician?

12. Does the resident need to have Advanced Directives for Health Care in place?
**Checklist for choosing a Nursing Home:**

13. What is the facilities policy on Do Not Resuscitate orders?

14. Is there a resident advocate available to discuss problems or concerns?

15. How long after admission is the resident plan of care written? Are resident and family involved in developing the care plan?

16. What is the cost of the services? What are billing, payment, and credit policies?

17. What hidden costs are there? Are there different costs for various levels of care or categories of service? How do you pay for additional services?

18. Are residents able to handle their own finances with minimal assistance of staff, if they are capable, or does a family member or outside party need to be designated to do so?

19. What is the policy on insurance and personal property?

20. What are visiting hours? Is there any restriction on when residents may receive visitors?

21. Is there a copy of the Residents Bill of Rights displayed prominently?

22. Does the facility accept non-ambulatory residents?

23. Does the staff receive dementia-related training?

24. Does the staff have an understanding of dementia-related behaviors? Do they accommodate behaviors without the use of physical restraints or sedatives?

25. Does the staff provide adequate supervision for confused patients?
Checklist for choosing a Nursing Home:

26. Would a marked change in physical condition require a transfer of your loved one to another part of the facility?

(Adapted Silin, 2001, Assisted Living Communities Checklist, Choosing a Nursing Home & Touring the Nursing Home)

The cost of living in a nursing home can be very expensive. The costs will be determined by the level of care needed, as well as the choice of a private or shared room, and other extras that might be available at that facility.

How to pay for the ongoing costs of living in a nursing home can be a challenge for all involved in the planning. To what degree the individual has the financial resources on hand or whether they have a long-term health care insurance policy will be part of the assessment necessary to determine if they can live at the facility they have chosen. If it is determined that financial resources are inadequate be sure to also consider if family members can contribute or if one of the government health insurance programs such as Medicaid can help pay.
Touring a Nursing Home…. with your eyes, ears, and nose.

1. Observe the Building and Grounds
   - Is the facility convenient for the family and the doctor?
   - Does the outside condition of the building appear to be kept up?
   - Is there an outdoor area for the residents to socialize?
   - Is the home near a bus stop? Are there other means of transportation available to the residents?

2. The Lobby
   - Is it attractive? Does it have a home-like atmosphere?
   - Is it being used by the residents? Can it be used by the residents?

3. The Residents
   - Are residents up, dressed, clean, and well-groomed?
   - Are there activities and are the residents involved in them?

4. Hallways and Stairs
   - Are all halls and stairs well-lit and clean? Are stairways clearly marked? Are exit doors clearly marked and clear of impediments?
   - Are they free of obstacles such as cleaning equipment, chairs and laundry carts (except when in use)?
   - Are floors clean and non-slippery?
   - Are seasonal or holiday decorations evident if appropriate?
   - Is there an obvious odor?

5. Residents Rooms
   - In which area of the home would your loved one be assigned a room?
   - Are rooms attractive, cheerful, clean, and well-lit?
   - How many residents share a room?
   - Is there a bedside stand, reading light, chest of drawers, and at least one chair for each resident?
   - Is the closet space sufficient?
   - Are the rooms air-conditioned?
   - Is there room to maneuver a wheelchair easily?
Touring a Nursing Home…. with your eyes, ears, and nose.

- Are residents allowed to bring some of their own furniture? Can they hang things on the walls?
- Are provisions made for privacy?
- Do doors or walls have name plates indicating who resides in each room?
- Are emergency call buttons or intercoms available in the rooms?

6. Bath and Shower Rooms
- How many residents share a bathroom? (Facilities built after 1974 must have one for every four beds).
- Do bathrooms have firmly attached handgrips or rails near all toilet and bathing areas?
- Do showers and bathtubs have non-slip surfaces? Do they have shower seats?
- Is there a call button near the toilet?
- Ask to see the shower or tub room.
- When and how often do residents receive baths?

7. Resident Lounge Areas
- How many lounge areas are available for residents?
- Is there sufficient space for visitors?
- Does the lounge area have other uses? Cleanliness of the room may be affected by other activities.
- Are the lounges comfortable and inviting?

8. Activity Programs
- Are activity calendars posted? How many activities are planned for each day, each week?
- Do the activities include a variety of interests?
- Are activities planned for room-bound or bedridden residents?
- Are arrangements made for residents to practice religious beliefs?
- Do residents participate in planning activities?
Touring a Nursing Home…. with your eyes, ears, and nose.

9. Occupational and Physical Therapy Rooms
   - Is there a variety of equipment? (parallel bars, stairs, whirlpool baths, walking aids, equipment for activities of daily living, weaving looms, etc.)?
   - Are the rooms clean?

10. Kitchen Area
    - Is the kitchen clean and well organized?
    - Does the staff handle food in a safe, sanitary manner? Is the food stored properly?
    - Does the staff wear hairnets?

11. Dining Area
    - Is the dining area pleasant, comfortable, clean, and easily accessible?
    - Are tables high enough for wheelchairs?
    - Are meals delivered to rooms of temporarily ill residents?

12. Menus and Food
    - What methods are used to keep hot foods hot and cold foods cold?
    - Does the food appear appetizing? Does it smell appetizing?
    - Is there staff intervention to find out why someone is not eating and to assist those who have not eaten?
    - Are residents who are unable to feed themselves being assisted promptly so that their food is at proper temperatures when they eat it?
    - Are food substitutes available for those who do not like or cannot eat the food served?
    - Are fresh fruits and vegetables served or does the facility only serve canned or frozen foods?
    - What provisions are made for residents who are ill and unable to eat in the dining room?
    - How often do residents eat? How often are snacks offered?
    - Are there menus for special dietary needs?
### Touring a Nursing Home…. with your eyes, ears, and nose.

#### 13. Staff
- Does the Nursing Home Administrator seem to know the residents? Does the administrator call residents by name?
- Does the staff show interest in individual patients?
- Is the staff courteous? Do they seem helpful, attentive, and pleasant?
- Is the staff attitude condescending or are residents treated with dignity and respect? Do they talk about residents as if they were not present?
- Is privacy respected? Does the staff knock before entering the resident’s room? Does the staff keep curtains drawn while providing care?
- Are calls for assistance responded to within a reasonable amount of time?
- Does the staff have CPR/First Aid training?
- Do they monitor the residents medical care/conditions?
- Do they reposition residents who cannot move without help?
- Is there enough staff to handle the needs of the residents? Do they seem overworked?

#### 14. Miscellaneous
- How soon does the facility notify families of any changes in the resident’s health, change of rooms, behavioral trouble, or of a transfer to the hospital?
- Is transportation provided for trips to hospitals, medical offices, or community functions? Is there a charge? What is the check-out procedure when a resident leaves the facility?
- Are podiatry and dental services available in the facility?
- What arrangements does the facility have for personal laundry? Are beauty and barber shop services available?
- Ask to see the Nursing Home Report. This is public information.
- Does the facility have high turnover ratios?
- Does the facility have a security system to warn staff if a resident wanders out?
- Are medications stored safely?
### Touring a Nursing Home…. with your eyes, ears, and nose.

- Does the facility allow pets? Permit smoking? Allow alcohol?
- Request a copy of the “house rules” and review it to see the limitations exceptions of the facility.

(Adapted Silin, 2001, Assisted Living Communities Checklist, Choosing a Nursing Home & Touring the Nursing Home)
RESOURCES

Activities

1. How Vulnerable Are You to Stress Test?

2. Do You Take Care of Yourself? Assessment for Caregivers.

3. How to develop an informal support network.
   Have each caregiver make a list on a piece of paper of all the daily tasks that they assist their care recipient with. With this list, make a daily and weekly schedule that contains tasks the caregiver can do and tasks that they need help with. Have the caregiver take this schedule to family members, friends, and neighbors and ask them to sign up for a time when they can help the care recipient with a specific task. This will help the caregiver to ask for assistance and have a time of respite each week.

4. The “Restoring Moments” that follow below are meant to be a creative way for caregivers to reflect on their caregiving experiences and explore new ways to deal with their grief.
RESTORING 1

It is time for you to grab your favorite cup and fill it with your favorite beverage.

Find your preferred place to sit. Sit down and take about five deep breaths, close your eyes, and just let your whole body relax putting every thought of unfinished tasks out of your mind for a few moments because this is your time to be refreshed.

Maybe you have a book or magazine you’re reading, or you just want to enjoy looking out a window at beautiful scenery. Whatever you find refreshing is what you need to do.

In order for you to be equipped to continue to care give you must take care of yourself by finding times of refreshment.

Contained within the “Restoring Moments” throughout the caregiving module are suggestions of resources that are uplifting and can be picked up at any time for encouragement. One such uplifting book is *The Caregiver’s Book: Caring for Another, Caring for Yourself* by James E. Miller.

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RESTORING 2

Today you feel as though you just cannot do this task one more time. You are tired of repeating the same sentences over and over again. You are tired of being misunderstood. You need to know that every caregiver experiences these same feelings. However, this is an indication that you need help from other people who can help relieve the load you are carrying. Maybe it is possible for you to have someone replace you one or two week-ends a month so that you could have some time to just go for a week-end outing with a friend or your family.

Take time to smell the roses and to listen to the birds sing sweetly in the trees or to the ocean gently lapping against the rocks on the shore as the trees wave in the gentle breeze.

Prepare your favorite meal and beverage that are only for special occasions because you are so special and are in need of tender care so you in turn can be ready to give care.

A special resource from which you may draw strength is *Quiet Moments for Caregivers* by Betty Free.
Hobbies can be a great diversion from caregiving. Maybe you like to sew, ride horse, swim, knit or crochet, write letters, make woodworking items, or just relax with a great book. Unreasonable expectations of needing a huge block of time sometimes prevents us from dedicating even a few moments of time to a hobby. Although you may spend a majority of your time caregiving or arranging for some aspect of caregiving, it is crucial that you spend a portion of your time doing something that you enjoy. Maintaining a balance in your life not only will benefit you but your loved one as well. All work and no play makes for a very dull day. With that said, your hobby becomes the perfect reason to take a break.

Treat yourself by leaving the hobby accessible, where you can make a moment count. This retreat from your busy schedule could be enjoyed to the fullest with soft music playing in the background and with the aroma of your favorite beverage close at hand. You will go back to the reality of daily commitments refreshed and encouraged.

Many times we just don’t understand all that is happening with the deteriorating condition of our loved one, but we can understand the sometimes negative changes in ourselves. Therefore, we must be sure to revive our souls by finding what works the best so we are refreshed and ready for the next day of caregiving.
Do you have a friend in which you can confide? Do you share what you are going through with someone?

It is very helpful to be able to talk to others, a person or a support group, who is or has experienced what you are presently encountering from day to day. Many times these people can share little tips with you that can be beneficial as you go about your daily tasks.

The more flexible you can be the less stress you will have to contend with in yourself. Being careful to not have expectations that are not attainable will also decrease the daily tension in your job of caregiving.

So many situations in caregiving are not predictable. It is important to understand that deterioration can and often will be occurring daily, either at a fast or slow pace. This is the part of life for you as a caregiver that is not predictable.

Therefore, do not be discouraged when you feel things are momentarily out of control. Instead invite a steadfast friend, who knows the journey of caregiving, over for a cup of a favorite beverage and a dessert.
There are times when caregiving causes you to feel as if you have failed. Maybe you spoke a sharp word or gave the recipient a harsh look because of being misunderstood or tired. This is very common. You must not carry this burden and don’t allow the seed of bitterness to grow within you as it will make you non-productive and your soul will become a desert.

Also, if the care recipient’s mind is slowly deteriorating many times they speak very harsh words to the caregiver. Unless the caregiver can constantly keep in mind that the words spoken can not be taken to heart, you may be very hurt and feel like a failure.

Remember this person is not accountable for their words and you are doing a wonderful job so take some time for yourself and do not receive any condemnation.

Your ability to be able to forgive anything in the past that has taken place between you and your care recipient will enable you to truly accept your role as an compassionate caregiver. Understanding that you can’t forget and that your care recipient may not be able to change is pivotal to you surviving the experience.
References


